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Woman finds her own answers to illness

By ALYSSA HARVEY, The Daily News, aharvey@bgdailynews.com/783-3257
Monday, October 1, 2007 11:11 AM CDT

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Leslie Witty's pain was all in her head.

"I've always been prone to headaches," the Warren County woman said. "I would take Tylenol or Advil and they would go away. It was nothing severe at all."

Then came the day her headaches became a more serious problem.

"More than three years ago, I was driving down the road with my little boy in the back seat," she said. "Suddenly, the whole left side of my body felt like I had put my finger in an electric socket. I thought I was having a stroke."

Witty wasn't having a stroke. She suffers from Chiari malformation, a serious neurological disorder where - according to the Chiari Malformation Syringomyelia News Web site at www.conquerchiari.org - the bottom part of the brain, the cerebellum, descends out of the skull and crowds the spinal cord, putting pressure on the brain and spine and disrupting the normal flow of cerebrospinal fluid.

"It felt like pins and needles - a shock sensation. When things were still, I felt a little off balance, like I was on a boat," she said. "Words came out wrong. I had memory issues, particularly with my short-term memory. Every time I turned my head side-to-side it made everything worse."

It would take three years for Witty to find the cause of the excruciating headaches and other symptoms that plagued her daily. The day she first felt the tingling sensations on the left side of her body, she saw a doctor, who thought a bone spur might be the cause of her ailment. He referred her to an orthopedist, who thought it was something else.

"He said, 'I don't want to scare you, but it might be (multiple sclerosis),' " she said.

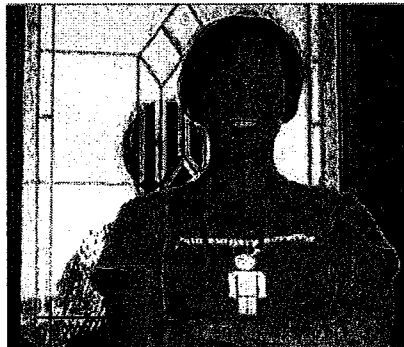
Her symptoms made her job as principal at Old Union School challenging.

"I was working the whole time. I didn't want to let feeling bad be my whole life," she said. "Until you experience it, you can't describe it to people."

In the meantime, she saw a variety of doctors, neurologists and headache specialists, had about 20 MRIs and was diagnosed with a variety of ailments, including complicated migraines. She even went to the Mayo Clinic in Minnesota, where doctors thought the headache was coming from her neck.

"They thought I should get shots in my skull to help manage the pain," she said. "It was awful. It didn't help."

Frustrated with the lack of answers, Witty began research on the Internet. She would type in key words from her MRI results and reports and the word "Chiari" kept coming up, she said. Then one day, she happened upon a message board that offered her some answers.



David W. Smith/Daily News
Brain surgery survivor Leslie Witty poses Friday at her Plano home.

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"Someone posted that a doctor in Australia who was an expert in Chiari would look at MRIs for free," she said. "I contacted him, and he e-mailed me within a week."

Knowing that a trip to Australia would be challenging, the doctor suggested she contact The Chiari Institute in New York. She went there in April and had tests and a special type of MRI called a cine MRI so they could see the movement of her spinal fluid.

"My spinal fluid got to a point and stopped, so every time I moved my head, my brain was hitting my skull," she said.

Because there wasn't enough room in her head, doctors decided to remove an area in the back of her skull to make more room. Witty was scheduled for surgery in June, but a week before the surgery doctors contacted her and told her they had found something else.

"I had a tethered spinal cord. It was adhered to the vertebrae and base instead of floating in fluid," she said. "My spinal cord was pulling everything down. Everything was 2-1/2 inches below where it was supposed to be."

Instead of brain surgery, Witty had an operation on her spinal cord June 1. Brain surgery was scheduled for Aug. 27. She didn't mind much, though.

"I was just relieved to know that something was causing this," she said. "(Doctors said) that if I hadn't done anything I could have eventually become paralyzed."

On Aug. 27, she returned to New York for brain surgery. She was hospitalized for a week and remained in New York for two more days to make sure everything was fine. She got a T-shirt that said, "I've got too much brain to contain" and began referring to herself as a "zipperhead."

"People who have this type of surgery call each other that because of the scar," she said, which runs from the middle of the back of her head to the base of her neck.

Witty said the staff and medical professionals at The Chiari Institute are amazing.

"They help people like me who have been told that there's nothing wrong," she said. "It takes finding a picture to show that something is going on."

Since she returned home, she has started physical therapy. She said she still feels stiff, but her spinal fluid is flowing and she's waiting for her muscles to calm down.

"Everything is in the right spot," she said, smiling. "They told me not to expect improvement for four to six weeks."


Witty said she has received a lot of support from family, which includes her husband, David, and their three children - Lia, 11; Caroline, 8; and James, 6 - and friends. She's looking forward to the day she can return to work at Old Union School.

"I miss it," she said. "I want to be out there."

Witty advises people who are searching for answers to mystery illnesses to become their own advocates.

"Sometimes you're forced to find your own answers. I feel blessed that I found people and a diagnosis so quickly. The average time for people to find out they have Chiari is usually six to 10 years," she said. "Get copies of MRIs and reports. Try to get as much information as you can. That MRI and report got me to this point."

— Witty has a blog about her experience. For more information, visit <http://wittybigbrain.blogspot.com>.

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Reader Comments

Shannon wrote on Feb 18, 2010 9:19 AM:

"My son had an MRI when he was 3 to check and see if he had a tethered cord. That came back fine but they detected the Chiari Malformation Type 1. He is now almost 7 years old and has had yearly MRIs. He has never had a symptom and when we went to his neurosurgeon yesterday for the results of his latest MRI, he said it looks as if he is outgrowing the Chiari. He compared last years scan to this years and you can see where there is less crowding around the spinal cord. I didn't even know it was possible to outgrow it. He specializes in Chiari and he said there are many different types. Some are considered birth defects, some appear after trauma, etc. As nature runs its course and the body grows, the skull can expand. We will still take precautions and go back for another MRI. I am still in shock but will believe it even more if the next MRI shows even more improvement."

angela w wrote on Nov 1, 2009 12:36 PM:

"I was diagnosed with Chiari in April of 2009 after having an MRI on my neck due to disk degeneration. I had the MRI done with flow study to see how much of my spinal fluid is being cut off. The herniation is 9 mm and I am having symptoms of left side electrical shock sensation, numbness in my face, severe headaches, and dizziness when I move my head up and down. The surgeon I am seeing for this doesn't seem too concerned and said "I'll keep and eye on it". Are these symptoms cause for concern? I'm having my disk fused November 12th and will this affect the Chiari? I hope someone can give me some answers."

shorty wrote on Oct 20, 2009 3:32 PM:

"I too am new to this blogging so bare with me. However I need guidance on wether or not to have the surgery. I was diagnosed 5 years ago and until this yr I have never had so much issues with the symptoms. So I have had several MRIs and a Cine study and the neurosurgeon that view the CINE report states that there is definitely some blockage of the fluid, so he recommended the surgery. However after reading some of others experiences with this surgery it scares me that maybe my symptoms aren't as bad to warrant the surgery. I have severe headaches, electrical shock sensations, my joints hurt, nausea, blurred vision,

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foggy memory, numbness to my left side of face. So yes when the symptoms get real bad I feel as though it should be done since it has put a damper on my life, and than when days are good I think maybe I can continue for a lil longer. However I'm afraid that if i don't i may be causing myself some serious neurological disorders, paralyzation or worse.....pls help does any way have any answers or advice.... "

NewtoChiariOne wrote on Jul 4, 2009 9:13 AM:

" cont:
you do not have MS, it is Chiari we are sending you to a surgeon. They did not describe it to well to me..or did they tell me how bad I have Chiari One. But I figure if I have to see surgeon it can't be good. I started looking up Chiari on web and it scared me more. From all the symtoms on the web I have at least 75% of them. I had been complaining to my doctors for years of how tired I was, and how bad my memory had gotten. Thanks to all your stories I now have hope. Best wishes to all.. "

NewtoChiariOne wrote on Jul 4, 2009 9:09 AM:

" Reading everyone's story gives me hope. I have been suffering from severe pain for about four years now and have not been able to work for the past three. I have been to countless doctors and they gave me a diagnols of Fibromyalgia. Drs has tried every drug to try to rid me of pain, nothing works. In Dec. 2008 I started getting shooting pains down my right leg, thought pinched nerve went to see Chiropractor had several adjustments they ran EMG said it showed pinched nerves in hips and shoulders. I quit going there because I was getting worse. All my limbs were completley numb, tingling, shooting pains, balance off, shoulder pain neck pain, have had bad mlgaines for years, always felt like something crawling on my scalp. Then the left side of my face went numb, that's when I thought ok I can not do this anymore. I contacted a nurolgist on my own, went to him had three different doctors see me on my first visit. They said they suspect I have MS, and was sending me for MRI on brain and cervical spine. After having the MRI they called me in two days and said no "

7yroidwchiari wrote on May 21, 2009 9:48 PM:

" My 7 year old son has just been diagnosed with 13-16mm herniation. He experiences headaches, occasional blurred vision. Other than that, he is pretty healthy and plays and interacts like a healthy boy. This was an accidental finding after he fell and hit his head on a step. He has been having headaches almost daily since Oct. 2008. Most days are very manageable. We have been to three neurosurgeons. One doctor told us to have surgery using his own dura that would be grafted from his own skull, if it was necessary to open the dura (this would be determined after removing 1/3 of his first vertebrae. Another doctor said he would have to open the dura to make room. The surgery was questionable and up to us to really make that decision. The third doctor said to wait. He is young and does not have enough symptoms to warrant having surgery right now. This doctor also said that he would use a synthetic patch and definately open the dura because that would be the main reason for having the surgery-to make enough room. We don't know what-to-do-now-help? "

021058 wrote on Mar 29, 2009 5:28 PM:

" I had my surgery over 3yrs ago chiari-syrg, I have to live with shoulder stiffness and neck stiffness, I have some nerve damage. I am in pain constantly, my back hurts the most. They prescribed pain management, but I don't think that will help!, I guess I have to live with the pain for the rest of my life! "

Georgina Arevalo wrote on Feb 3, 2009 12:55 PM:

" I am so glad I was up watching mystery diagnosis! I am thrilled to read your story among many others. I have been dealing with terrible symptoms for the last 4yrs. I've been told "theres nothing wrong". I just got a Chiari diagnosis (with a 10mm herniation) 2mos ago and I was just told I need surgery but my surgeon doesnt have any experience. And on top of that I have not had several MRI's or Ctscans to check for other problems that may come from Chiari. I've been to the hospital twice before thinking I was having a stroke. I wake up with numbness form head to toe on my left side and have terrible pain. I was watching Mystery Diagnosis with Marissa Irwins case...and I saw they went to the Chiari Institute..I will make an effort to go! God Bless! "

Michelle wrote on Feb 1, 2009 4:44 PM:

" Your article was was really good, I had the same operation on the 17 December 2008, I flet great afterwards and was able to sneeze and cough without the discomfort of any pain. Unfortunately I contracted viral meningitis and was hospitalised over the new year period for 2 weeks. I am starting to feel a lot better in myself now but was relived to find out that I was not the only person suffering from this horrible malformation. Like yourself I felt as though I was having a stroke and on the odd occasion by hip bones would really ache in bed. I also found that when I returned home from work or shopping I could not walk for long periods of time around the house. I am pleased I have had the operation as I could not go on any longer with the pain and also I was addicted to coedine tablets (this was due to taking the medication on a daily basis to help with the pain), I am slowly getting myself off the tablets and hope that things can only get better. "

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